

Hepatitis C in Wales: Perspectives, challenges & solutions



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Foreword

When I established The Hepatitis C Trust back in 2001, I did so because I felt that, as someone who was living with hepatitis C, I didn't have access to the kind of support and information that I needed. I also felt like there was nobody speaking on my behalf. People like me seemed invisible.

In the years that have followed, the central mission of The Hepatitis C Trust has continued to be providing a voice for people with hepatitis C and others affected by the virus. We have come a long way in recent years, but significant challenges remain. People with hepatitis C are still living with stigma and are still coming into contact with professionals who often have very little knowledge of hepatitis C. We still have huge numbers of people who remain undiagnosed and therefore at risk of serious liver damage and painfully few people have been treated and cured.

This report, which we have produced after engaging with patients and professionals across Wales¹, provides the voice to those affected that is so important, and highlights some of these key issues. But as well as outlining some of the key challenges that we face, it also provides a note of hope and positivity. In Wales, significant progress has been made in recent years and we are now seeing more people than ever before treated for hepatitis C. We must ensure that this progress continues.

My dream is for there to be no need for The Hepatitis C Trust to exist. I want to close our doors because we have been made redundant thanks to the elimination of hepatitis C. With the clinical community, Welsh Government, Public Health Wales, third sector organisations and patients all working together in partnership, I am confident that Wales can truly take the lead and make sure this dream becomes a reality.

Charles Gore

Chief Executive, The Hepatitis C Trust



Background

- 12,000 – 14,000 people in Wales are living with hepatitis C.ⁱⁱ
- An estimated half of all people who inject drugs in Wales have hepatitis C.ⁱⁱⁱ
- 900 people are expected to receive hepatitis C treatment in Wales in 2016/17.
- In May 2016, the UK Government pledged its support for the WHO's goal of eliminating hepatitis C as a major public health threat by 2030.^{iv}

For a combination of reasons, hepatitis C is a virus that is much misunderstood, and which suffers from a lack of awareness and knowledge among professionals and the public at large, despite its status as a serious public health issue.

An estimated 12,000 – 14,000 people are currently living with hepatitis C in Wales, with around half still undiagnosed. It is one of the three main causes of liver disease, the only one of the five 'big killers' in Wales and England where deaths are rising.^v Over the last decade, hospital admissions for hepatitis C-related liver disease have nearly tripled, with deaths doubling.^{vi} With around 100,000 people across the UK not diagnosed, hepatitis C really is a silent epidemic, and represents a significant public health challenge.

However, the recent introduction of direct acting anti-viral drugs provides the opportunity, so rare in public health, to actually eliminate the virus as a major public health threat, in line with the UK's commitment, by 2030. These treatments, unlike older interferon-based treatments, have short treatment durations, very high cure rates, and little or no side-effects.

Wales now has the opportunity to lead the way by developing and implementing its own distinct strategy for eliminating the virus. With a national Liver Plan in place^{vii}, a manageable burden of disease, a dedicated clinical community, and a host of organisations and bodies committed to tackling the virus, Wales is well-placed to capitalise on the opportunities afforded by the increasing availability of the new treatments, and to ensure that the virus is eliminated by, or even in advance of, 2030.

This report, produced after a series of interviews and focus groups with patients and professionals, maps out some of the main issues affecting people with hepatitis C in Wales, and makes recommendations for key actions to ensure continued progress in the journey towards elimination.

Living with stigma

People with hepatitis C in Wales, and across the UK, are disproportionately drawn from some of the most disadvantaged and marginalised groups in society, and three-quarters of people with the virus come from the lowest two socio-economic quintiles.^{viii} Groups primarily affected include people who use or who have used drugs, migrant populations (in particular South Asian and Eastern European communities), men who have sex with men, prisoners, and homeless people (in



“When I was first diagnosed I was told not to tell anyone. As I got older and as I lived with the virus for longer I never quite got over that. I always felt a sense of shame and, even now that I’m cured, I suppose I still do.”

addition to people who may have been infected via NHS contaminated blood). As such, many people with hepatitis C already face societal barriers and challenges that can have a severe psychological impact, such as stigmatising attitudes and behaviours.

Compounding this, those patients with whom we engaged highlighted the

stigma of hepatitis C as an additional and significant psychological burden that they have to live with, a burden which was particularly pronounced upon first being diagnosed and which often led to catastrophic losses in self-esteem and self-worth, as well as feelings of shame and guilt.

Some, who were diagnosed decades ago, told of how they were instructed not to tell anyone else of their diagnosis, and of the years of internalised guilt that resulted. Others spoke of having knowingly waited years before even being tested, such was the stigma (as well as the fear) that surrounded a potential diagnosis and the prospect of having to tell family and friends of how they may have contracted the virus.

Specific situations were highlighted, situations which seemed common to the experience of many people living with hepatitis C. Visiting the dentist was one such common example. People with hepatitis C reported always being booked in for the last appointment of the day, apparently to allow time for dental practices to undertake additional infection control practices. Such practices left people feeling as though they were in some way distinct from the rest of the population, and as though they posed a danger to others.



“Stigma can seem like a really fluffy or invisible concept, but when you experience it you know how real it is. It’s something that sits inside you, clouds your thoughts and dictates your actions.”

Health professionals, too, highlighted to us the impact that stigma can have, with some believing that stigma prevents at-risk individuals from accessing testing and care. For some people with hepatitis C, they reported, the sense of guilt, shame, or in some way feeling “dirty” manifested itself in disengaging with care entirely despite being aware of their diagnosis, such is the psychological stress they felt placed under and the mental health issues that sometimes resulted. If unable to share the concerns, stresses and fears of entering the hepatitis C care pathway with those around them, many simply choose not to – a decision that greatly increases the risk of liver cirrhosis or cancer.



“We need to make clear that it doesn’t mean you’re sinful, it doesn’t mean you’re immoral, it doesn’t mean you’re dirty, it doesn’t mean you’re undeserving, it just makes you ill. Lots of people have hepatitis C – we have to reinforce that. Those of us who have had hepatitis C are just like every other person on the street.”

Such barriers to the care pathway can often be overcome through the use of peer support, whether through support groups or ‘buddying’ schemes where patients are accompanied to their appointments by a trusted and trained peer worker.

Some patients spoke about the difference that had been made to their lives when



“I think maybe that people might think stigma isn’t as big an issue as it might once have been, and maybe it isn’t. But having lived with hepatitis C for so long and having had the same feeling of shame and dread for such a long time, it still feels the same to me. Only my partner knows I have hepatitis C. I just couldn’t face telling anyone else.”

they made the decision (often having seen and heard others talk about their experiences) to speak out freely about their diagnosis. For them, being open about having hepatitis C not only meant that their personal psychological burden had been lifted, but also meant that they were better able to tackle head-on some of the prevailing stigmatising societal attitudes that exist towards hepatitis C, by having

conversations with people about the virus and acting as educators within their own community.

They also stated their belief in the need to ‘normalise’ hepatitis C, in order to tackle the stigma that still exists. By undertaking positive media campaigns, for example to highlight the cross-section of people living with the virus, they believed it was possible to challenge the misconceptions and stigma that still surround the virus.

Professional education

Given the stigma experienced by many people with hepatitis C and the problems that lots of people have in dealing with their diagnosis, it is essential that they experience positive engagement with the health professionals involved in their care. For some, it may be the only opportunity that they have to discuss living with the virus, and obtaining the facts, information and key messages they need is all-important.



“When visiting my GP, I often felt like I was the one who had to educate him about hepatitis C, which was really worrying. Luckily I’m the kind of person who researches everything for myself, but if I wasn’t then I would have really struggled.”

Patients from across Wales highlighted the outstanding quality of care delivered to them by the hepatology teams involved in their care and the gratitude felt towards these specialist teams, for both their expertise and the way in which they provided care, was apparent.

However, a consistent source of frustration for patients remains the low knowledge levels that they felt were often displayed by other health professionals, with a repeated complaint being the low standards of knowledge and awareness at primary care level.

Many patients had spent years visiting their GP with a variety of symptoms but had not been offered a hepatitis C test, despite often having clear risk factors. Others told of how they were given incorrect advice and information regarding living with the virus, information which was often stigmatising and left them feeling less inclined to discuss their diagnosis and less likely to stay engaged in the care pathway.

Another issue brought up repeatedly by patients was the misinformation that they had been given by their GPs, both upon first diagnosis and throughout their patient journey.

Some, for example, cited misinformation they had been given by their GPs related to the sexual transmission of hepatitis C, something which heightened the feelings of anxiety and stigma that they already experienced. The



“The hepatology team that cared for me were incredible and made sure I knew exactly what options were available to me. They involved me in my care, and were a massive source of support. I felt like we were a partnership and we managed to cure me together.”

effect of this low level of knowledge is twofold. Firstly, it means that (primarily in the primary care environment) opportunities to test and diagnose are often missed, due to a misunderstanding of symptoms or risk factors. Secondly, it means that people living with hepatitis C can often face stigma when engaging with services.

For example, one person spoke of being admitted to hospital for an issue unrelated to hepatitis C but being told by a nurse that hospital staff would not enter the

patient's hospital room unless the staff were fully 'gowned', because of her hepatitis C diagnosis. Such stigmatising (and misinformed) behaviour causes great distress and is the direct result of a lack of professional education with regards to hepatitis C.



“Every drug worker, every sexual health service worker, every prison officer, and every probation officer should at least have a working knowledge of hepatitis C. If they don't, then - it may sound harsh - but they can't be doing their job properly.”

Health professionals, too, expressed concern that knowledge levels among relevant professionals did sometimes fall short and said that additional activities could and should be undertaken in order to address this current gap in knowledge.

However, Public Health Wales was commended for its work to drive up professional awareness of the virus in order to help facilitate an increase in the numbers of people tested and diagnosed.

Finding the undiagnosed

As we move towards ever-increasing availability of new hepatitis C treatments, the focus in Wales is starting to shift towards finding the undiagnosed. With around half of all people in Wales with the virus still undiagnosed, it is clear that significant amounts of work are required in order to find, diagnose, treat and cure all of those living with the virus.



“If someone is registering for the first time at a GP, test them. If someone goes to A&E and is getting blood taken, test them. Let’s think of all the chances we have to get people diagnosed. and let’s use them.”

This work poses many challenges. Due to its often asymptomatic nature, hepatitis C is a virus that can easily go undiagnosed for decades. Even when symptoms are present (such as fatigue, poor memory, abdominal pain, dry eyes, and irritable bowel or bladder) these are often misdiagnosed or

dismissed (both by patients and professionals), and people are often not tested for hepatitis C when they present with such symptoms.

The health professionals that we spoke to were aware of the need to significantly increase the numbers of people getting tested and were concerned that key opportunities to test at-risk people are currently being missed. Primary care was identified as one area where much more could be done to test people, particularly those people who are unlikely to otherwise be offered testing, such as people who may have been infected with hepatitis C through historic drug use but who may not have used drugs for several decades. These individuals are unlikely to be engaged with substance misuse services, and may not even consider themselves as being at risk, given that they may have only ever injected drugs on a handful of occasions many years ago.

One method suggested of increasing the numbers of people tested and diagnosed in primary care was an increase in joined-up working between primary care and secondary care, through the visits of blood-borne virus (BBV) nurses to GP practices to deliver awareness training to GPs and primary care nurses. Such an approach, it was suggested, would both increase primary care staff’s knowledge levels and help to improve pathways into care as well as increase the numbers of people being offered hepatitis C tests.



“One group we need to start testing is performance and image enhancing drug users. These guys, and they are usually guys, don’t consider themselves to be at risk, even though they definitely are. It’s difficult to approach gyms, though, as they obviously don’t want to talk about their members using drugs.”

Other opportunities to test people which are currently not being utilised include antenatal testing. Under current guidelines, pregnant women are tested for hepatitis

B and HIV but not hepatitis C, despite those at risk of hepatitis B and HIV generally also being considered to be at risk of hepatitis C as well.^{ix}

Another key at-risk group who, it was suggested, may currently be failing to access testing are users of performance and image-enhancing drugs. Anecdotal evidence suggests that the sharing of injecting equipment is common among this group and that many users are resistant to the idea that they are at risk of hepatitis C and other BBVs.



“I think we are getting there in terms of testing, but we need to make sure testing provision is consistent across Wales. There is still too much variation across services.”

With many of this cohort not accessing relevant services (e.g. substance misuse services), they also miss out on key prevention messages, meaning that they may not even realise that they are at risk

of contracting the virus. Indeed, only around 32% of users of performance and image-enhancing drugs have undergone testing for hepatitis C.^x

It was clear, though, that substantial work is being undertaken in order to improve the numbers of people being tested in substance misuse services. It was highlighted that the Welsh Government, for example, has recently included within its *Working Together to Reduce Harm: Substance Misuse Delivery Plan 2016 - 2018*^{xi} the introduction of ‘opt-out’ BBV testing in substance misuse services. While there are, given the varying levels of testing provision across drug services in Wales, significant challenges related to the implementation of this policy, it could represent a seismic shift forwards, given that around half of people who inject drugs in Wales are estimated to have hepatitis C.

Access to treatment & cure

The single biggest factor that has brought the elimination of hepatitis C in Wales within reach has been the development of new hepatitis C treatments. These treatments, which can cure the overwhelming majority of people with hepatitis C, are truly transformational and offer us the rare opportunity to rid Wales of a killer virus.

While older, interferon-based courses of treatment could last 48 weeks or even longer, were injection-based, and had severe short, medium and long-term side effects, the new treatments can be as little as 8 – 12 weeks in duration, are taken in pill form, and have little or no side effects. They allow people to continue working and to continue leading their ordinary lives, something that older treatments often did not.



“It’s difficult to put into words how amazing it is to be free of hepatitis C. I know now that the way I felt before – the ailments, the depression - wasn’t actually me. It sounds like such a cliché but I feel like having been cured I have my life back. I’ve got a second chance.”

Whereas Wales has in the past lagged behind the rest of the UK in terms of the numbers of people accessing hepatitis C treatment, this situation has reversed in the past year, with access to new treatments in Wales now being wider than ever before.

After the Welsh Government initially agreed to provide funding for 360 people to receive the new treatments in

2015/16, further agreements have been reached which mean that 900 people will be treated in 2016/17 – a significant increase and one which will transform and save the lives of people across Wales who are living with hepatitis C.

The ability to access treatment was a key issue for all of those patients with whom we engaged. For those who had experienced older, interferon-based treatments, there was a hope expressed that nobody else should have to suffer the hardships and pain (both physical and mental) of undergoing such treatment when alternatives were available. For those who have been treated and cured with the new treatments, there was enormous gratitude for being able to access such highly effective regimens which they were able to tolerate with minimal or no side-effects.



“I was lucky, in a strange way, that my liver was in a bad way so I was near the top of the queue for the new treatments. I can’t imagine how frustrating it might be to have to wait for them. Sometimes your liver might be okay but hepatitis C has a much wider impact – I think that has to be recognised.”

There was, though, a strong sense expressed among patients that access to these new treatments should not be dependent upon the severity of damage to the liver alone, and that more attention should be paid to the extra-hepatic impact of hepatitis C when treatment guidelines and protocols are developed and revised. The physical impact of hepatitis C, they stressed, was not just focused on the liver, and the virus

can lead to a range of other physical ailments such as joint pain, renal issues, bowel and bladder problems, as well as mental health issues ranging from 'brain fog' to severe depression.

Given the agreement reached earlier in 2016 to provide treatment to 900 people in 2016/17, there was a profound feeling of satisfaction among health professionals regarding the progress that has been made around access to treatments. There was



“Being able to treat almost everyone is incredible. It’s why we do what we do, and it’s a huge step forward from where we were.”

also a keenness to ensure the long-term viability of this ambitious approach to treatment, with a need for confirmation that the all-Wales approach would be continued. Such an assurance would not just allow services to better plan treatment

delivery, but would also mean that equality of access to treatment across Wales was ensured and that any potential future ‘postcode lottery’ was avoided.

It was clear from discussions that there also exists significant scope to increase the number of outreach treatment services delivered in Wales. While historically hepatitis C treatment and care have been delivered in a secondary care setting, the ease of the new treatments means that they are ideally suited to be provided in a community setting, such as a drug service or a GP practice. Providing treatment in this way also makes it easier for groups who are traditionally considered ‘hard to reach’, such as injecting drug users and homeless people, to access treatment and, crucially, to stay engaged in the treatment pathway rather than drop out.

While community-based treatment does currently exist in some areas of Wales, there is more to be done to ensure that treatment is made as accessible as possible to people who may face financial, logistical or psychological barriers preventing them from accessing secondary care-based treatment.

Key recommendations for action

In order to maintain the progress that has been made in tackling hepatitis C in Wales, The Hepatitis C Trust encourages all relevant Welsh stakeholders to work together to ensure:

- A commitment to the elimination of hepatitis C as a serious public health concern is included within the Welsh Government's forthcoming Public Health Bill.
- The implementation of a public awareness campaign aimed at tackling stigma around hepatitis C and at encouraging individuals to access testing.
- A continuation of, and long-term commitment to, the successful all-Wales hepatitis C treatment protocol, which ensures equal access to new, highly effective treatments for increased numbers of people.
- An increase in the number of community-based treatment services, in order to ensure access to treatment for groups who traditionally find services difficult to access.
- Full implementation of an opt-out approach to BBV testing in substance misuse services, as set out in the Welsh Government's *Working Together to Reduce Harm: Substance Misuse Delivery Plan 2016 – 2018*.
- The utilisation of opportunities, such as mandatory GP education days, to deliver BBV training to key primary care professionals.



"We have to look at this like it's a war, and at hepatitis C like it's our enemy. We do now have the weapons in place, we just have to be ready to fight for elimination."

References

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